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ABSTRACT

This paper contains preliminary findings from a 1989 survey of over 400 rural health programs serving chronically ill, handicapped, or high-risk children. Respondents identified major problems affecting service delivery. Follow-up research is continuing, but present data indicate that transportation problems, for both clients and staff, will probably have the highest ranking. Other frequently reported problems were: (1) issues related to recruitment, retention, and training of personnel; (2) limited program capabilities due to lack of stable funding, escalating medical costs, demands for documentation of services, and time demands; (3) inadequate referral sources in the community and insufficient locally-based resources; (4) family reluctance to utilize services, poor provider-family communications, cultural and language barriers, and social problems such as poverty and illiteracy; (5) lack of skilled physicians, physician unwillingness to accept children with special needs or low-income clients, and slow diagnostic and referral mechanisms; (6) lack of public awareness about how to identify and refer a child with special needs; (7) need for case management, interagency service coordination, and family and child follow-up; (8) need for articulated and coordinated state-regional-local systems; and (9) lack of access to tertiary (specialized) services. Program strategies developed to address these problems are listed. (SV)

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RURAL HEALTH CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS: RESULTS OF THE 1989 NATIONAL BUREAU OF MATERNAL AND CHILD HEALTH SURVEY

INTRODUCTION

The purpose of this paper is to describe a 1989 study of rural health programs serving handicapped, chronically ill, and high risk children. The study was funded through a Bureau of Maternal and Child Health and Resources Development SPRANS (Special Project of Regional and National Significance) project with the Georgetown University National Center for Networking Community based services.

The Bureau of Maternal and Child Health (BMCH) has had an initiative to develop community-based family centered care for a number of years. In a close alliance with former Surgeon General C. Everett Koop, multiple innovative urban and rural strategies have been developed across the nation. Current efforts are focusing upon dissemination and evaluation of existing community-based family-centered programs.

It is now necessary to critically examine rural health issues both within the context of the existing BMCH efforts and the emerging P.L. 99-457 efforts. It is the intent of this study to provide essential data for rural planners, program administrators, practitioners and families.

This BMCH funded study involved a nation-wide survey of over 400 actual local health programs. This paper will describe methodology and a discussion of major problems and strategies identified by the programs. Data analysis will be complete by Summer, 1990 at which time more definitive information will become available.

Many of the ACRES membership either work directly with health programs or coordinate services with health providers. It is hoped that the information in this preliminary report will lay further groundwork towards collaboration between education and health, enabling joint understanding of problems and workable strategies.

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STUDY METHODOLOGY

The basic instrument was designed to reach actual local rural health programs serving special children and provide descriptive data.

The instrument addressed the following questions:

1) What is the nature of the delivery systems which provide health care to rural children?
2) What eligibility criteria are attached to rural programs for children with special needs?
3) What types of conditions affect children with special needs in rural areas?
4) What types of services do these programs make available to these children in rural communities and how helpful are these services from the perspective of the programs surveyed?
5) How are rural health services to this population funded?
6) What are the problems faced by programs trying to provide rural health services to children with special needs?
7) What strategies and resources have programs found useful?
8) What ideas or recommendations do programs have for improving services?

To avoid restricting programs, we allowed respondents to self-define their program as rural. Children with special needs were defined as having handicapping conditions, chronic illnesses, or high risk indicators. Three types of rural health programs were tapped for information: those which are free-standing community clinics, those which are outreach clinics from a tertiary medical center, and those connected to state systems (Developmental Disabilities, Title V [CSHCN], etc.) Rural programs included those which were housed in such areas as farm and migrant communities, small towns and villages, reservations and mountainous regions. We were looking for programs which had multiple components and therefore avoided (as much as possible) eliciting information from private single-practice physicians.

Finding programs was a difficult, tedious task. Initially, we sent a letter and return post card to all Title V Maternal and Child Health and Children with Special Health Care Needs (CSHCN) Directors, 99-457 Part H coordinators and Interagency Coordinating Council (ICC) chairs, community clinics and rural hospitals referred by the National Rural Health Association, rurally-based SPRANS/MCH Demonstration Projects, and MCH Regional offices. Attendees at a 10-state rural conference, the second National Surgeon General's conference rural presentation, and the Region IV & VI Surgeon General's Conference also received the letter. This query involved 310 persons.

From this effort 1,402 program names were received. To these, questionnaires were mailed along with a return mailer. It is important to note that of these 1,402 program names, we had no idea how many would actually fit our criteria and complete the questionnaire. Of the 1,402, 583 (42%) returned the questionnaire . Of the 583, 434 (74%) completed the questionnaire, and 149 (26%) responded that they either were not rural or did not serve the specified population. 21 were returned as non-deliverables. We are following (by telephone) 3 states which did not respond and 7

states which had a low return. An additional mailing to these newly identified programs as well as approximately 275 other programs will be completed by March 1, 1990.

Of the programs which completed the initial questionnaire, some had a very high visibility. These included Minnesota, New York, Oklahoma, Oregon, West Virginia, and Washington. Of particular interest to note is the information from the more frontier states. (Hawaii, Idaho, Montana, North Dakota, South Dakota and Wyoming)

A preliminary look at the data returned yields information about categories of problems and strategies (questions 6-8 above).

CATEGORIES OF PROBLEMS AND STRATEGIES

Problems and strategies most strongly identified to date include: transportation, personnel issues, limited program capabilities, insufficient community-based resources, family socio/environmental concerns, physician issues, public/family awareness/ education, coordination of services, organizing a state-regional-local system, and access to tertiary care.

Transportation

Problems

Transportation problems, well-known to all who work with rural families, will probably have the highest ranking in the returns. Problems involve the families, program staff, and vendors (i.e., those providing equipment such as respiratory, intravenous, etc.). There seems to be not only a lack of funding for transportation, but non-availability as well. Children ride buses for long periods of time. Families have great difficulty traveling to the tertiary centers. There is no public transportation and families are quite a distance apart. Traveling to visit children often drains staff energy. Geographic barriers; i.e., mountains, snow, and seasonal road conditions all contribute to transportation problems.

Strategies

Programs have developed some solutions to their transportation dilemmas. These include utilizing donated funds to facilitate transportation, providing limited transportation on a case by case basis, having vendors travel to the homes, and providing mileage payments and taxi fares.

Personnel Issues

Problems

Staffing of local programs is, at best, difficult. Issues of recruitment, retention, working short-staffed, low salary and benefit packages, assuring competency, and stress are paramount. Personnel shortages were reported with nurses and pediatric nurse practitioners, physical therapists, registered dieticians, occupational therapists, speech pathologists, teachers, infant interventionists, physicians and social workers. Shortages led to such problems as not having enough staff time to provide assessments in a timely manner and inadequate service time. Travel incentives and rural life style affected retention. Training needs were important especially in the area of educating professionals to identify problems and providing specialized care.

Strategies

Programs have developed strategies to deal with personnel issues; i.e., upgrading skills of nurses to work with high risk infants and families, providing intensive training for case managers and consultants, and using professional staff rather than paraprofessionals. Training maximizes credibility. One program offered that it was the dedication and alertness of their staff (including non-professionals) that provided the extra support and information that families needed. Broad utilization of the public health nurses (PHN's) provides programs with abilities to provide parent support, education, developmental assessments/interventions, resource/referrals and coordination of services. Keeping abreast of all community services is most helpful.

Limited Program Capabilities

Problem

A large percent of respondents state that their rural programs lacked a stable funding base. They saw populations increasing with expansion to meet the growing need quite difficult. Monies were needed to pay for travel and lodging, reimbursement for medical services, acquire adopted equipment and other capital, and provide staff. Services which were seen as requiring increased funding included: itinerant services, preventative services, at home services, outreach programs, long term health care, pharmacologic therapy, and nutrition services.

Further, local programs were limited in capability by demands to document services, delays in obtaining medical information, and time demands.

Funds were limited due to insurance reimbursement restrictions on some providers (like PNP's), escalating medical costs, competition for funding, need for more payment resources than medicaid, difficulties processing bills, provision of uncompensated services, and sliding scale for services.

Strategies

Few strategies have yet been identified which address these funding concerns. One program stated that they accepted any means of payment and sometimes no

payment. Another said they were able to receive payment for medications and treatment supplies.

Insufficient Locally-Based Resources

Problem

Local health programs identified inadequate referral sources in the community as a major problem. Either the resource was lacking or the level and intensity was inadequate. These included OT, PT, speech, social services, school programs, audiology, dental, specialized nursing care, infant stimulation, institutional care for children who are medically fragile, and appropriate hospital resources. Support programs such as respite, day care, babysitting, therapeutic recreation, parent support groups, parent networking, and mental health were strongly lacking. Respite was the strongest single needed service identified.

Cited were problems developing new services in the community, long waiting lists, lack of summer programs, time required to obtain needed services, high fees, family attitudes towards rural services, and lack of integration of public and private sectors.

Strategies

Rural programs have many innovative ways of tapping resources and creating resources. Listed among resources often receiving referrals from rural health programs were:

1) A major university program for children with disabling conditions
2) Public school programs
3) Early intervention council in the county
4) Project which provides no-cost OT and PT
5) School nurses
6) Public health centers
7) An adolescent residential program for substance abuse
8) Developmental day placement
9) Community hospital and staff
10) Head start
11) An early intervention program

Having a knowledge of resources available assist all programs. Tertiary (specialty) resources will be discussed in another section.

Family Socio/Environmental Concern .

Problems

This section of problems addresses family capabilities and resources. Programs cited problems working with families due to family reluctance to apply for services, poor provider-family communication, family discomfort with services and not understanding the program, transiency leading to inability to keep families in the service area long enough to be effective, difficulty finding families at home, and distrust of outside helpers.

Parent coping skills, home environmental problems, high rates of functional illiteracy, inadequate social support, isolation from other families experiencing similar problems, disenfranchised, disintegrated families, adolescent single poor mothers all contribute to family need.

Financial problems have an especially devastating impact on the rural family's ability to care for a child with special needs. Children are not taken to doctors due to lack of medical insurance and high cost of services. Families who have income too high to qualify for medical cards have much difficulty accessing specialty care.

Family income is further compromised if accessing medical care causes parents to lose jobs if work time is missed. This can be the case when parents must take time off to drive long distances to access specialty care.

The family ability to follow through with appointments was cited by a number of programs as a major problem. This has been attributed to parent education and motivation, financial concerns, and commuting distance. Many stated that tracking children once they had been referred to another program was difficult. Therefore, families are lost in the system.

Cultural issues come into play, as well. Lack of bilingual and bicultural care at tertiary centers, cultural barriers with migrant populations, gaining acceptance with minority populations, and language barriers presented important challenges.

It is important to note that only program staff were surveyed. No families were asked for their impressions as this work has been left for future study. This, no doubt, leads to a skewed impression of family difficulties working with programs.

Strategies

Many programs have demonstrated a sensitivity to family needs. Strategies from assuming an advocacy role for families to providing direct support services have been undertaken. One program stated that they specifically designed the program to the family needs. Another offers a regularly scheduled parent support group. Other strategies included:

1) Providing parent training
2) Providing guidance to families and assistance in using the services offered by the agency.
3) Going to the families to do intake, service planning, supportive counseling, etc.
4) Placing an emphasis on follow-up
5) Conducting in-home assessments at no cost

Cultural issues were addressed by those interacting with minority populations. Some use counselors proficient in the parent's native tongue; some employ paraprofessionals who are native speakers; some utilize outreach workers from the community or population served; one employed Spanish-speaking nurses. Having sensitivity and familiarity with the predominant culture and language is essential.

Physician Issues

Problems

Multiple issues impact the provision of medical/physician care close to home to these children. Often families must drive a considerable distance to access services. Although there are many specialty care outreach programs, many programs identified a deficiency in this area. Concerns included inadequate medical facilities for evaluation close to home, finding qualified medical specialists within a reasonable distance, and accessing pediatric subspecialty services. Local (non-specialty) physician needs were also expressed. A sparsity of skilled physicians, a lack of developmentally trained pediatricians, and lack of local quality primary medical services were named. Physicians who demonstrated a "fatalistic attitude" about the illness or its treatment, an unwillingness to accept children with special needs, a refusal of medicaid payment or low income clients, or an inability to communicate openly with families and service providers caused much difficulty. In addition, programs identified problems communicating and developing linkages with local physicians. Slow diagnostic and referral mechanisms were impediments. Lack of physician follow-up caused concern. One program identified that their local physicians resisted referring patients to "public" medical services for well child care.

Strategies

Some programs are dealing effectively with these physician issues. Strategies employed are:

1) Communicating openly with the child's primary physician
2) Advocating for the family/physician relationships
3) Utilizing private sector physician for full 7-day a week coverage
4) Providing for on-going medical follow-up and referrals
5) Enabling the medical community to become familiar with program services

Public/Family Awareness/Education

Problems

This area of concern addresses child find issues. Gaining community cooperation in referral efforts can be most helpful, but overcoming stigma and apparent lack of concern can be difficult. Gaining political awareness can be a problem as well as overcoming resistance to public medical services. Hospitals (especially newborn nursery staff) and local physicians could be helpful, but can be uncooperative. Lack of awareness of how to identify a child with special needs as well as education about services available are causes of problems for parents and community representatives as well.

Strategies

Programs have recommended a number of awareness strategies which they have found useful. Reliance upon information spreading via "word of mouth" works well.

Informing churches, pharmacies, public health nurses, social workers, the medical community and all other agencies is important. Many indicated that county-wide screening helped them reach families and recommended that these be conducted as joint endeavors among agencies. One program stressed that screening be advertised as appropriate for all children, not just for children about whom the parents have concerns.

Coordination of Services and Interagency Concerns

Problems

Case management, coordination of services, and family/child follow-up all were described as needed and often lacking components within local programs. Finding staff who could provide coordination is difficult as is securing funds for case management.

Interagency issues lead to turf battles and duplication and gaps in services. There is a strong need for coordination of efforts across public agency lines both at local and state levels. A lack of interagency agreement to share resources can cause real problems leading to inadequate communication and role confusion.

Strategies

But, some programs have found workable ways to address the need for service coordination. They have assigned case management staff to track clients in outlying areas, provided home and community based case management and developed information and referral systems.

Interagency coordination has been one of the strongest recommended practices by local programs. Working closely with other agencies (public, private and philanthropic) can be done on a formal or informal basis. Interagency models discussed by programs included:

1) Quarterly meetings to update one another on services available
2) Working together in an informal case management structure
3) Conducting annual interagency screening
4) Locating services near one another
5) Interagency administration and funding
6) Contracts for funding
9) Utilization of technology for networking
8) Working closely on child find

State-Regional-Local Systems Development

Problems

Articulated, leveled and coordinated state-wide systems for delivery of health care are ideal but are problematic and cumbersome in states. At the county level there are inconsistencies in eligibility in service delivery and counties where no clinics

exist. Some local programs have difficulties interfacing with state bureaucracies such as state Title V programs and WIC programs. Jurisdictional problems exist where native Americans reside. When regional offices have to approve families for eligibility, the process of application can be slowed by layers of personnel.

Lack of an organized state-regional-local system increases the length of time it takes to get a family into the system.

Strategies

Regional centers were utilized by many programs. These centers provide diagnostic evaluation services, and coordination of services and monies to create new services. Programs felt that good working relationships with state level departments were important.

Access to Tertiary Centers

Problems

Last, but not least, tertiary (specialty) access is an important component of care for many of these children. Many families must drive great distances to access care and not only have difficulties finding transportation, but also paying for lodging, accessing timely appointments, and feeling comfortable in the city. Tertiary providers can "lack rural sensitivity leading to unreal expectations." The expense of delivering team care on an outreach basis can be prohibitive to some programs.

Strategies

Programs which have nurses who provide coordination to and from the tertiary center and referrals to high risk follow-up clinics have addressed the problem. Many stated that bringing the specialty care to the local communities via mobile units was an advantage. Using community facilities for outreach clinics was also a model as well as encouraging vendors to establish satellite operations and establishing branch offices of major programs in small outlying communities. All in all, locating service in the community was seen as beneficial.

CONCLUSION

By adhering to current time lines for data analysis, we will be able to provide a comprehensive tabulation for presentation at the ACRES workshop. If there are unanticipated delays, results will be made available to all attendees at a later date.

This data will provide a basis for future decision-making. We also intend to establish a nation-wide network to these health programs. This will enable them to assist one another and share resources.